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ABSTRACT

The second of five volumes on the means by which Canadian communities can reduce the incidence of mental retardation, minimize existing impairment, and improve the quality of life of the mentally retarded, this booklet focuses on needed action to assure the health of babies, young children, and families. After an introduction, sections deal with the following topics: lifestyles and physical environments; importance of early identification and response; prenatal diagnosis; treating genetic disease or avoiding its complication; screening and early intervention of newborns and young children; regionalized reproductive care systems; the regionalized program in Southwest Ontario; preventing handicaps in the children of teenagers; the St. Paul Maternal and Infant Care/Adolescent Health Services in St. Paul, Minnesota; immunization; community responsibilities; helping parents who have just found out their child has a mental handicap; parent support groups; training and education for parents; government support for families who want to keep their handicapped child in the home; respite care/in-home support; the Community Respite Service program; and social and physical integration. (DB)

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MAKING A DIFFERENCE:

What communities can do to prevent mental handicap and promote lives of quality

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Volume II: The well-being of babies and young children

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MAKING A DIFFERENCE
The well-being of babies and young children

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CANADA

MAKING A DIFFERENCE:

What communities can do to prevent mental handicap and promote lives of quality

Volume II: The well-being of babies and young children

National Institute on Mental Retardation

NOTE

The examples and stories in **Making a Difference** are about real people and real situations. In some cases the names of individuals have been changed to avoid unwanted attention to families and children. We do encourage you, however, to contact us at NIMR if you would like to receive more information on a specific example or story.

Dedication

Making a Difference is dedicated to Dr. Ronald J. Christie who spearheaded the involvement of the National Institute on Mental Retardation in the field of prevention. His death, in 1985, was a blow to the movement for persons with mental handicaps. Among his other accomplishments, Dr. Christie had also been an NIMR Associate, a former Vice-President of the Canadian Association for Community Living, a past President of the Metropolitan Toronto Association for the Mentally Retarded and a member of the American Association on Mental Deficiency.

Dr. Christie was a general practitioner in London, Ontario and a member of the Faculty of Medicine at the University of Western Ontario.

We believe that **Making a Difference** is a manifestation of Dr. Christie's hope that NIMR would take a leading role in not only helping to prevent mental handicaps, but also in promoting lives of quality for persons with mental handicaps.

Photographs

The photographs in Making a Difference are meant to illustrate certain situations and do not necessarily represent specific individuals or events. Photographs of specific persons, however, are acknowledged.

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PREFACE

In May, 1983, the Canadian Association for Community Living (formerly the Canadian Association for the Mentally Retarded) convened a group of approximately twenty people from across Canada in order to review developments in the field of prevention, to discuss the role of CACL and its member provincial and local associations in the field of prevention, to gain a better understanding of the role of the federal government in the field of prevention, and to develop a feasible action plan for future CACL involvement in this area. This symposium, made possible largely through a grant from the Health Promotion Directorate of Health and Welfare Canada, was the culmination of several years' work on the part of CACL. Since 1976, CACL had had a committee responsible for the area of prevention, and in 1979, when the CACL's Board of Directors conducted a major self-evaluation of the association's goals and structure, prevention was identified as one of the major directions to be undertaken by CACL.

The national symposium concluded an extensive two-and-a-half year consultation process with all regions of Canada through which a nationwide consensus had developed regarding the need for CACL to serve as a national coordinator and clearing house for information as well as a lobbyist at the federal level and provider of technical support. CACL would be supported in this role by its National Institute on Mental Retardation.

A significant contribution to the conceptualization of the problem was made at the symposium by Ron Draper of Health and Welfare Canada. Mr. Draper outlined a prevention strategy model developed by the World Health Organization (WHO) which he applied and adapted in his Directorate. Indeed, it was the presentation of this model which enabled the symposium to integrate CACL's interest in prevention within the context of the organization's overall concerns.

The WHO model suggests that prevention strategies can be implemented at four levels: the level of impairment, the level of disability, the level of handicap and the level of feedback.

Impairment refers to a physiological or psychological loss or abnormality which would impair physical or mental function. Disability is a consequence of an impairment or a circumstance which prevents individuals from performing their social roles. Handicap refers to a disadvantage resulting from an impairment or disability that limits or prevents the fulfillment of social roles. The concept of feedback refers to situations where further impairments and disabilities are acquired as a result of handicapping circumstances.

This approach fit in very well with CACL's concerns which focus primarily on individuals living with a mental handicap. Consequently, the notion of working not only to prevent impairment from occurring but also to minimize existing impairment and promote lives of quality for individuals provided the impetus for **Making a Difference.**

Although in **Making a Difference** we do not use the WHO terminology in such a specific way as described above, the WHO model provides the framework for these publications.

Making a Difference is a series of five monographs which address how communities can reduce the incidence of impairments which cause mental retardation and also how they can reduce those disabilities and handicaps which are environmentally caused – often by where people live or work or go to school.

A heartfelt thank you is extended to the Prevention Project Resource Team who developed the framework and content of this series, and to the staff of the National Institute on Mental Retardation for producing the final documents.

Sincere appreciation is offered to Dr. Maureen Law, Associate Deputy Minister, Health and Welfare Canada and to Mr. Ron Draper, Director General, Health Promotion Directorate, Health and Welfare Canada, for their support and direction in the process which we hope will "make a difference" for thousands of Canadians.

Robert H.A. Haslam, M.D., F.R.C.P. (C)
Chairperson
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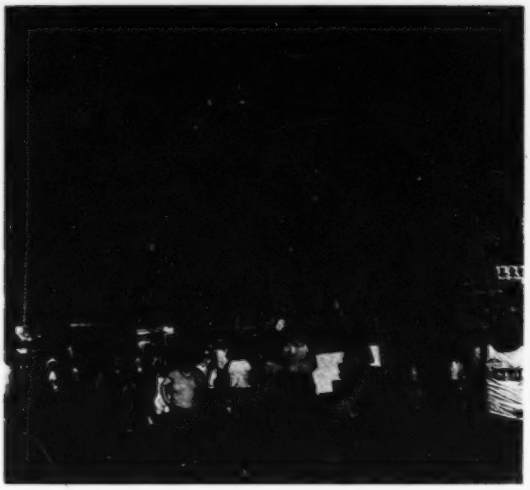
and
Prevention Project Research Team, NIMR

INTRODUCTION



As the baby-boom generation of the 50s begins to have their own families, a great deal is being written and discussed about what to do before, during and after having babies. Today's parents want to read everything they can about pregnancy, childbirth and child rearing. In fact, there is a second baby-boom of sorts. Mothers and fathers want their sons and daughters to have the best of everything. They want to prepare for a mentally and physically healthy baby, right from the start.

However, no matter what precautions are taken, some babies will be born with handicaps. In many cases, the cause will be unknown.

But there is a great deal that can be done to prevent mental handicaps before conception, during pregnancy and labour, and while the child is growing up.

We can discuss the prevention of handicaps at a number of levels. The good health of the parents, even before they conceive a child, may play a large part. The nutrition and general environment of the pregnant woman is another factor in the well-being of an unborn baby. And probably the most essential element is the environment of newborns and young children, which can prevent a handicap from occurring at all, or lessen the impact of an existing handicap.

When we talk about preventing mental handicap in the early years of life, we must look at health, safety and the social environment, with a focus on the following areas:

- Our lifestyles and physical environments:
  We hear a great deal about the misuse of alcohol, drugs and tobacco before and during pregnancy. It is now widely accepted that these substances have detrimental effects on unborn babies. The same can be said of improper eating habits of pregnant women and young children.

  Another cause of mental handicaps in the early years of life is accident or injury to an expectant mother or to a young child. For example, there is no excuse for not using seatbelts or safe child-carrier seats in cars.
- Health care:
  During the last few decades, most North Americans have had access to the latest advances in medicine and health care. There are, however, times when lack of proper health care can cause mental handicap or heighten its impact. For example, children or prospective mothers may not be immunized, or pregnant women at risk of having handicapped babies may not be identified.
- Family building:
  We hear more and more about the importance of the family in helping children develop into adults who are emotionally, physically and mentally healthy. The same is true of the family of a person with a handicap. In fact, the importance of a family in the life of a handicapped child is even more significant. Taking children away from their families or not providing adequate support for children to stay with their own or alternative families can cause further handicap.
- Social and physical integration:
  The movement towards getting people out of institutions and into the community has arisen because separating people with handicaps from their family has been proven to be harmful. Young children with handicaps who associate only with one another are likely to progress more slowly than those who associate with non-handicapped children in their neighbourhood. Isolation and separation in the early years can have a devastating effect on later development.

OUR LIFESTYLES AND PHYSICAL ENVIRONMENTS

We are constantly being warned about things that are bad for us. We shouldn't drink, we shouldn't smoke, we shouldn't eat red meat, we shouldn't drive without our seatbelts. It seems that everywhere we look, there are carcinogens, toxins and radiation. How do we cope with that? How can we control the situation so that our children are affected as little as possible?

The answer to these questions may be the solution to many of the problems of the last few decades. It may also be beyond our grasp for the time being. There are, however, some areas that we can explore and influence now. Certain lifestyles or practices do increase the risk of having a child born with a handicap or of developing one:

- taking unprescribed drugs, smoking tobacco, drinking alcohol;
- not eating properly and not gaining sufficient weight during pregnancy;
- being exposed to toxic substances;
- keeping poisonous or dangerous objects within the reach of children;
- not supervising youngsters in play or in sports;
- being under a great deal of stress during pregnancy or during the child's early years;
- not receiving adequate medical care;
- having children at a very young age or near the end of child-bearing years.

These situations are a result of many factors, but may be attributable to:

- patterns of public safety and health;
- opportunities which are physically, socially and economically accessible to people;
- peer pressure to drink or smoke;
- social pressure to discipline children in certain ways;
- personal choices and habits;
- living or working in hazardous places;
- public policy and practice that does not effectively discourage damaging lifestyles.

Taking action

Lifestyle is generally perceived as a matter of individual choice. Many attempts to alter behaviours have simply been education campaigns such as "Buckle up for Safety"; anti-smoking and anti-drinking advertising for pregnant women; and "Have you hugged your child to-day?" campaigns.

In trying to prevent mental handicap and its impact, attempts to alter lifestyles and physical environments should:

- educate people about what is harmful;
- eliminate the causes of harm.

With these goals in mind, we can then attempt to bring about:

- a significant decrease in the use of tobacco, alcohol, drugs and medications by pregnant women and by prospective mothers;
- adequate nutrition for pregnant women and prospective mothers;
- safe homes and play environments for young children;
- safe automobiles, streets and highways;
- a decrease in pollutants and hazardous materials;
- the elimination of the abuse of children;
- easy access to quality health care;
- good family planning, especially by teenagers and women over 35.

More specifically, we can work with governments and community action groups to promote:

- public education about the risks associated with the misuse of alcohol, tobacco and over-the-counter drugs;
- adequate funding of alcohol and drug treatment programs;
- strict standards and penalties so that we can have safe and non-polluting workplaces;
- control of industrial pollution;
- rigorous identification and elimination of toxic substances, such as lead paint, airborne lead, or waterborne mercury compounds;
- compulsory use of seatbelts and standardized infant car seats;
- severe penalties for impaired driving;
- comprehensive secondary school driver training programs;
- more stringent requirements for obtaining and maintaining a driver's license;
- expanded lead poisoning education for physicians and the public, and increased screening efforts by government;
- health education programs relating to specific high risk groups such as teenagers, poor people,

women over 35 years of age, and women with extreme weight problems;
- family planning services and clinics in high schools;
- updated high school curricula teaching family planning and the prevention of mentally handicapping conditions in the context of general health and lifestyle issues;
- effective research into the effects of toxic substances and nutritional supplements and diet on pregnant women and unborn babies;
- better nutrition through public education on known nutritional hazards, accurate consumer information about processed foods, and selective supplementary diets for high-risk and breast-feeding mothers;
- increased access to appropriate maternity services for women at high-risk.

As individuals, particularly as future, present or expectant parents, we can have a direct influence on our children's intellectual and physical health by:
- reducing our consumption of drugs, alcohol, tobacco and any other stimulants or depressants;
- maintaining a high standard of nutrition throughout our lives;
- keeping our homes and workplaces free from hazardous materials, such as lead, radiation, poisons and herbicides;
- taking advantage of proper health care services and practising responsible family planning throughout our lives;
- following proper safety measures in our homes and communities, including the use of seatbelts and correct infant car seats;
- teaching our children wise behaviour during play and sport;
- arranging proper medical supervision for ourselves during pregnancy and labour, and for our children during their early years;
- coping with stress effectively, both when pregnant and when raising our children.

TAKING CARE OF OUR HEALTH

In our health-conscious society, we are constantly reminded to stay as physically fit as possible. We have our yearly check-ups and our Pap smears, and monitor our blood pressure. Although these may seem routine to most of us, they take on added dimension when they relate to pregnant women and newborn babies. The quality of health care they receive can determine whether a baby will be born with or will acquire a mental handicap.

Equally important is the quality of health care received by babies born with handicaps. The absence of such care can cause further handicap.

One way of ensuring that quality health care is received is to inform parents and prospective parents about what they can expect and what they can do. We can also advise physicians and other professionals on how they can be most helpful.

Many of the things that parents can do are suggested to them by physicians and other professionals during routine visits. These recommenda-

tions reflect the physician's or professional's attitude toward mental handicap. For example, if he or she offers encouragement and asserts that there is hope for a child's future, the parents are more likely to take steps to lessen the impact of a handicap on their child. This is not to say that parents should have unrealistic goals; only that they should not set limits on what their child may accomplish.

Although attitudes play a large part in preventing further handicap, when we refer to health care, we are generally concerned with preventing conditions which cause handicaps or making sure that existing conditions do not lead to handicaps.

Conditions which can cause handicap are divided into three areas:

- genetic and prenatal (before birth);
- perinatal (during birth);
- postnatal (after birth) and early childhood

The causes of mental handicap within these three periods are being studied and very often prevented through:

- early identification and diagnosis; and
- regionalized health care systems.

The importance of early identification and response

Prospective parents should know what may be harmful during pregnancy, and what constitutes a safe environment for the growing child. Early identification is complex, and requires action during all key periods of a child's life, including before conception and in the womb, then as a newborn and an infant.

Prenatal diagnosis

Perhaps the greatest area of technological advancement, but also of controversy, is that of prenatal diagnosis.

Through ultrasound, fetoscopy, radiographic visualization, amniocentesis, chorionic villi biopsy, and maternal blood samples, the promise of early detection of potential problems is great. Chromosomal anomalies, sex-linked disorders, biochemical disorders of metabolism and major anatomical malformations can be diagnosed.

Fetal visualization and tissue sampling, however, is primarily for parental assurance. It has enabled thousands of couples at risk for malformation or genetic disease in their children to undertake pregnancies which otherwise would not have been attempted. It reassures them that a given problem does not appear to exist. In the few cases when one is identified, this early detection

provides the couple with an opportunity to plan and adopt a supportive course of action most appropriate to their personal and family needs.

Treating genetic disease or avoiding its complication

If a prenatal diagnosis does reveal that there is or could be a problem, there are techniques for treating genetic disease or avoiding further complications (Milunsky, 1983). These include:

- avoiding exposure to certain substances or conditions which are causing the problem;
- following a restricted diet, for example as in PKU, a condition which can lead to mental handicap;
- supplementing one's diet with vitamins;
- undergoing certain drug therapies;
- having surgery, for example to remove tumours or to place intracranial shunts.

One example of a successful program is the Quebec Network for Genetic Medicine (Scriver, 1985) which provides genetic screening, diagnosis, counselling and treatment for approximately 30 genetic disease conditions. Operated by four universities in that province on behalf of the Ministry of Social Affairs, it has three working principles:

- *participation by citizens is voluntary;*
- *communication between regional centres, the laboratories network, parents and their physicians is encouraged;*
- *ongoing research and development precedes the development of new services and is used to evaluate components of existing programs to determine if they should be maintained or altered.*

The program encompasses biochemical testing for mass screening of blood and urine spots collected on filter paper; rapid follow-up of positive screening tests; confirmation of positive screening tests and interpretation of diagnostic tests; and counselling and treatment.

The program's 16 years of service to Quebec communities have been characterized by positive and widespread support from physicians. A survey of mothers revealed virtually unanimous approval for its methods of preventive screening.

One of the indications of the program's responsiveness to needs was its screening for Tay-Sachs carriers. This was shifted from the Jewish community at large to the high schools, resulting in a participation rate increase from 15% to 75%.

The Quebec Network for Genetic Medicine also tests for B-thalassemia and sickle cell carriers in the Italian, Greek and black communities where these conditions are most prevalent.

Taking action

Health care givers should be encouraged by concerned individuals to take the following courses of action:

- There are numerous valid and reliable screening methods which identify a wide variety of conditions. Such tests need to be systematically used.
- Some tests and risk predictors have not been fully evaluated. They should be.
- Early screening and identification must be linked to effective intervention programs.
- Parents need to be involved in the screening and identification process and be fully informed of any findings.
- There must be careful surveillance of all pregnancies, labours and deliveries. There must be a management plan for all high-risk pregnancies, improving intrauterine environment and fetal surveillance. A multidisciplinary team approach is necessary for pregnancy management, since there are a variety of psychosocial, environmental and educational issues in addition to medical problems (Harrigan, 1980).

Screening and early identification of newborns and young children

The screening and early identification of newborns and young children can be facilitated by observing the child's physical, intellectual, communication, social and emotional development. Recognizing a mental handicap early will:

- make it easier to prevent more serious disabilities;
- assist parents and friends to work toward improving children's abilities;
- enable children to receive the services best suited to their needs, abilities and potential;

- prepare children for educational services.

Regionalized reproductive care systems

The May 1982 Report of the Ad Hoc Committee on National Strategies released by Health and Welfare Canada, identifies the leading causes of death at birth as perinatal oxygen deficiencies, birth injuries, difficulties during labour, and abnormalities of the placenta and the cord.

Some reasons for these problems are:

- the baby's low birth weight;
- the age of the mother at the time of pregnancy (i.e., teenager or over 35);
- viral diseases in the first three months of pregnancy;
- smoking;
- alcohol and drug abuse;
- improper diet during pregnancy;
- an unsafe environment during the delivery;
- failure to take advantage of proper prenatal and obstetrical care;
- lack of early and adequate supervision during the pregnancy;
- failure to take advantage of a system of regionalized perinatal care.

These difficulties have led to numerous task force recommendations for regionalized, systematic reproductive care, involving early, sustained, quality prenatal care and close monitoring and supervision during delivery.

An ideal health care system would include family planning and safe maternity care for all women before conception, and at conception, and for both the unborn baby and the mother during pregnancy and birth. A comprehensive health care system must also be in place for the child during his or her early years of development.

If we combine the suggestions and recommendations of many leading authorities and organizations, the result would be a regionalized reproductive care system similar to that illustrated on the opposite page.

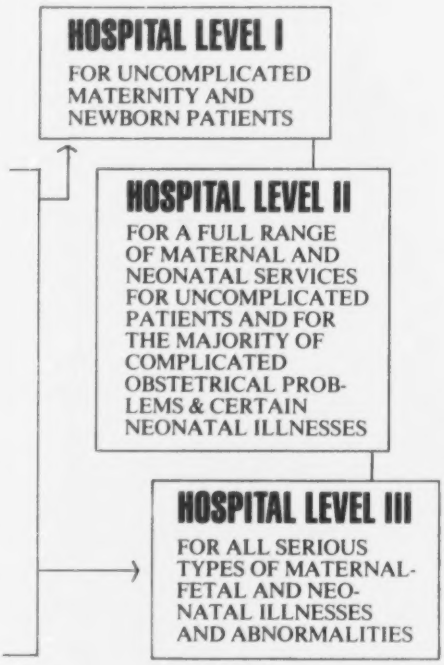
A regionalized program in Southwest Ontario

A regionalized reproductive care program which resembles the model on the opposite page based on public and professional education has evolved in Southwest Ontario during the past ten years. The need for good prenatal nutrition, health maintenance and health care are stressed in prenatal health classes held in all communities in the region which are attended by the great majority of first-time pregnant mothers and many of those who have previously had babies. It is recognized that although special efforts are made to reach teenagers and unmarried mothers in most communities, this is not uniform and efforts are being made to improve this particular service.

Professional education has been developed through an Outreach Program based on the regional teaching centre through which all hospitals in the region are visited by a team comprised of a nurse, neonatologist and obstetric perinatologist at least once a year. Both combined and separate programs for nurses and physicians are offered in each hospital. Participation is entirely voluntary but use of the program is extensive. Topics discussed in the hospital programs in-

A REGIONALIZED REPRODUCTIVE CARE SYSTEM

in such a system, there is early and regular contact by the expectant mother/ prospective parents with an accessible health care system; routine visits to a physician who has access to quality health care services


HOSPITAL LEVEL I
FOR UNCOMPLICATED MATERNITY AND NEWBORN PATIENTS
HOSPITAL LEVEL II
FOR A FULL RANGE OF MATERNAL AND NEONATAL SERVICES FOR UNCOMPLICATED PATIENTS AND FOR THE MAJORITY OF COMPLICATED OBSTETRICAL PROBLEMS & CERTAIN NEONATAL ILLNESSES
HOSPITAL LEVEL III
FOR ALL SERIOUS TYPES OF MATERNAL-FETAL AND NEONATAL ILLNESSES AND ABNORMALITIES

at each level hospital, MULTIDISCIPLINARY TEAMS, including:

- nurse-practitioners
- a health aide
- obstetrician-perinatologist
- nutritionist
- neonatologist
- pediatrician

as well as ANCILLARY SERVICES, including:

- social, psychological and educational/vocational counselling
- special nursing support
- nutritional education and food supplements
- telephone consultation
- health education programs

continuing regular contact between mother and child with health care professionals

COMMUNICATION

- telephone and ambulance link-up between specialists and hospitals
- basic and continuing education for physicians, nurses, and other allied health personnel in perinatal health care
- efficient and safe transfer of patients to the appropriate level hospital
- *ONGOING COMMUNICATION AND CONSULTATION BETWEEN ALL THREE LEVELS OF HOSPITALS*

clude family-centred care, assessment of fetal/maternal health, complications causing risk to the mother or fetus in pregnancy, newborn resuscitation, newborn assessment, breast feeding and various newborn illnesses. The management and outcomes of all mothers and their babies who are referred to the Regional Centre are discussed at Teaching Rounds in each community hospital.

The program has succeeded not only in ensuring that the majority of mothers with complications and their high risk unborn babies are cared for in hospitals with necessary staff and facilities, but also that they are referred back to their own communities as quickly as possible. Importantly, very few sick newborns now require transport after birth. In the Regional Centre, special efforts are made to integrate the babies into their families by encouraging close and regular contact with parents, siblings, grandparents and other close relatives and family friends. The view held is that no infant is too immature or sick not to benefit from the love of his or her family.

Mrs. Morris lives in a town about 100 miles from the Regional Centre. She was 32 weeks pregnant when her son was born weighing 1600 grams. At her family physician's request, she was

transferred to the Regional Centre where Neil was born. He required immediate resuscitation and developed complications immediately after birth, requiring assisted breathing. Now he is a bright typical four-year old, except that he is speaking two languages. His mother subsequently became pregnant, went into premature labour at 26 weeks and was again referred to the Regional Centre for her second birth. Her daughter, Theresa, was 26 weeks gestation and weighed 770 grams when she was born. Like her brother, she had problems which could have left her severely handicapped had she been born where the necessary skills and facilities were unavailable. However, she has done well and when last seen at age two years, her performance in all ways was similar to any two-year old child, despite the fact that she was three months premature.

Preventing handicaps in the children of teenagers

Studies indicate that the children of teenage mothers are more likely to have a lower birth weight, placing them at risk of developing additional problems. The following describes a program which has been effective in helping to prevent handicaps associated with teenage pregnancies.

The St. Paul Maternal and Infant Care (MIC)/Adolescent Health Services (AHS), St. Paul, Minnesota

The St. Paul MIC/AHS is one approach that clearly works, and proves that a public high school is an ideal location for adolescent prenatal health services, since the educational, psychosocial and medical needs of the adolescent can be addressed on the premises.

The project involved a junior-senior high school located in the inner city of St. Paul. In 1973, 40% of its 1,002 students belonged to minority races, as compared to only 4% in the overall city. The drop-out rate was 30%, double that for the city as a whole, and absenteeism was the highest of all St. Paul schools. The incidence of pregnancy in 15 to 17 year olds was three to six times higher than of girls the same age in St. Paul as a whole. After giving birth, 45% of the girls dropped out of school, setting the stage for future deprived home environments.

The project organized the services, five mornings per week, of a team in the school consisting of a family planning nurse clinician, a clinic attendant, a social worker, a physician along with a pediatric nurse associate, a nutritionist, and a maternity nurse clinician. Dental hygiene, health and home economics were also offered, as was family planning counselling, V.D. and pregnancy testing, Pap smears, immunization, and personal counselling and referral. A pilot educational program in human sexuality designed specially for junior high school adolescents was conducted jointly by the project and the St. Paul Public Schools.

In the first three years of operation of the school-based clinic in two St. Paul high schools, pregnancies declined by 40%. Moreover, 25% of the female students had come for family planning, and 87% were continuing birth control three years after coming into the program.

The project proves that school can be the best care setting for a pregnant adolescent. Having a clinic in the school helps to meet the two main requirements of a program to provide care for pregnant teenagers: the clinic is both accessible and inviting to the often hesitant care seeker; and its convenience keeps her coming back (Steinman, 1979).

Immunization

Young children are often at risk of contracting a number of childhood diseases which can be life-threatening or mean life-long impairment. Medical advancement has eliminated or drastically reduced the incidence of many such diseases through immunization.

This most important form of prevention has often meant long years of research in vaccine development by teams of scientists and physicians.

One disease currently affecting young children is Haemophilus Influenzae type b, which is the leading cause of bacterial meningitis in North America and Europe. It is thought to be a major cause of acquired mental handicap and usually attacks babies and children under five years of age.

Of these children, 75% are under two.

The fatality rate of the disease is 5%, with meningitis, epiglottitis and pneumonia being the major causes of death. Haemophilus Influenzae meningitis can also result in permanent neurological damage even when prompt treatment is available. Damage can involve hearing and vision loss, motor abnormalities, seizures and mental handicap.

Connaught Laboratories Ltd., a Canadian company, has been conducting research on a new vaccine to prevent Haemophilus Influenzae type b disease. Considering that 75% of Haemophilus Influenzae type b infection occurs in children under two years of age, the most significant feature of Connaught's vaccine is its ability to induce a high level of immunity in this younger age group. This is a feature not displayed by any other vaccine for this disease. It is expected that when this vaccine becomes available in the near future, a major cause of acquired mental handicap can be prevented.

Is your community doing everything possible? An overview

Dr. Allan Crocker (1982) of Boston has developed an overview of many of the current practices found to be effective in the prevention of mental handicaps. Can you answer these questions about your community?

1. Is immunization against rubella (German measles) mandatory and accessible?
2. Do doctors whom I know about do everything they can for at-risk pregnancies, including managing diabetes and high blood pressure?
3. Do local hospitals use special care for premature infants, including newborn intensive care units?
4. Is genetic counselling available through physicians, health care centres or hospitals, to families I know for whom there have been known problems?
5. Do I see educational material advising against drinking alcohol during pregnancy?
6. Do I know of any child in this area who has been exposed to lead poisoning?
7. Is Rh-antibody testing performed on all couples I know who are expecting children?
8. Are the members of my community aware of the importance of using proper infant car seats whenever they take their child out in the automobile?
9. Is family planning taught in local high schools, and is counselling available to reduce the incidence of teenage pregnancy?
10. Are child abuse and neglect actively combatted in my community, through agencies educating the public and monitoring families who are suspected of or prone to problems?
11. Is an effective health and nutrition education program in place and visible in my community and its schools?
12. Have the parents of all the newborns I have known been instructed about correctable inborn errors of metabolism, such as having the child's urine sampled for PKU on his or her fourteenth day at home?
13. Have all of the newborns I have known been screened for hypothyroidism?
14. Have my friends who are carriers of genetic conditions been aware of the fact, before becoming pregnant?
15. Are neighbourhood children with mental handicaps identified at as early an age as possible, and provided with intervention and stimulation to minimize the handicap?

16. Are area families with a member who is mentally handicapped given services and support which enable them to keep the child in their home, and integrate him or her into our community?

17. Does my community support continuing research into the causes of mental handicaps, perhaps through active participation in contributions to United Way and other fund-raising campaigns?

18. Do I feel that my physician and the professionals with whom I come into contact, for example my children's teachers, are as informed as possible about the prevention of mental handicaps, and the promotion of lives of quality for those who have mental handicaps?

Answering this questionnaire has perhaps revealed some weaknesses in your community. By working together, making others aware of the problems, we can make a difference.

FAMILY BUILDING

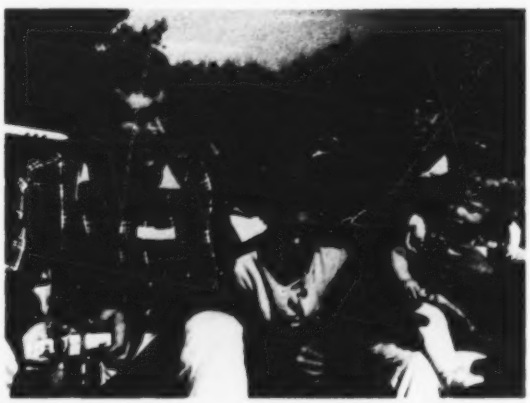
The notion of "family" has recently been resurrected by those wishing to return to more traditional values and lifestyles. When we speak of families, we may tend to think of the typical two-parent, 1.8 child, two-car garage situation. However, this stereotype has undergone radical alterations. A growing number of families are headed by single parents, and this will likely increase in coming years. Many families are run by working couples and this trend, too, is expected to grow.

More and more families require supports to help them raise their children. These are not necessarily families with handicapped members but families who are trying to cope in a stressful world. We must recognize that these supports should help build or consolidate bonds and relationships between parents, sons and daughters.

Whether a child is being raised by "two-car garage" parents or by a single, working parent, the relationship between that child and family members can determine his or her future, and indeed, the future of the family. This is particularly true of children with handicaps, since their needs may place more stress on those around them.

What characterizes a positive and loving parent-child relationship? Here are some indicators:

- the parent enjoys being with the child;
- the parent can sense and respond to the child's behaviour cues;
- the parent knows about games, toys and activities which are suitable for the child's stage of development;
- the parent generates independently a wide range of interesting activities which will further the child's development (Bromwich, 1976).



Although loving relationships in natural families should be encouraged and supported, there are times when a child's natural family may not be the best place for a child. In such situations, the child can be raised within an "alternative" family who, for all intents and purposes, become his or her "real" family.

By the time Cindy was 16, she had experienced life only in institutions. She had been labelled as "severely mentally retarded with behaviour challenges." Fortunately for her, some people in

her community were able to see that beneath this label was a young girl who longed for a family to call her own. She needed love and a feeling of belonging far more than therapy and higher staffing ratios.

A couple named Carl and Sharon, who had other teenagers, were interested in having Cindy live with them. They had no professional education about persons with handicaps. They did, however, understand how critical it is for a child to have a family of her own.

It took dedication and effort, but now Cindy goes hiking, camping and eating out with a real family — her family! She attends a local school with other kids her age, and is active in her neighbourhood.

Cindy has been involved with her new family for five years now. She has brothers and sisters, and is even an aunt. Sharon has become her guardian, so Cindy is assured of having a mom and a dad who will continue to love her for many more years to come (Strully, 1985).

Despite such wonderful success stories as that of Cindy, everything should be done to help natural families stay together as much as possible. If parents are given adequate information when their child is born or diagnosed as having a handicap; if they receive adequate support in their home; if they have adequate financial resources; if they can take a break from raising their child once in a while; then chances are that they would be far better equipped not only to keep their child at home but also to foster the child's growth and development.

When parents find out their child has a mental handicap

When parents first find out about their child's handicap, the role of the professional who is involved can be crucial. That person can determine the attitudes of the parents and in turn influence the development of the child for years to come. Here are a few suggestions on developing better communication between parents and professionals and encouraging positive attitudes towards children with handicaps:

- Professionals should know their own strengths and weaknesses. They should try not to impose their weaknesses on the families they work with.
- Decisions should be based on the assumption that if the decision is incorrect, it will have the least dangerous effect on the child and family.
- If something doesn't work, it should not be assumed that it is the fault of the family but rather the fault of the program, service or activity.
- It should not be assumed that all families need emotional counselling or parental training. These services should be available to families who want them.
- Under no circumstances should parents be told that "nothing can be done"; services should be provided to prepare all persons, regardless of age or handicap, to live, work and spend leisure time as independent children and adults in the community.
- Parents should have full access to all diagnostic and educational information. Programs used by the family should be held accountable for their effectiveness based on the child's progress.

New approaches to working with families of handicapped newborns are being developed to better meet the needs of all those concerned. The following are examples of such an approach.

Infants born with spina bifida (myelomeningocele) are frequently operated upon during the first day of life before appropriate formal counselling can occur so that parents are often unable to obtain emotional support and comprehend the impact of the anomaly. They do not have a chance to get to know their baby. A recent study, however, has shown that surgery can usually be safely delayed for up to one week in order to allow the parents to bond with their infant and to be actively involved in the decision-making process in an informative, supportive and "non-urgent" atmosphere (Charney et al., 1985). As a result, the parents feel like they are members of a real family that has had some opportunity to be together.

The Alberta Children's Hospital in Calgary is a good example of how a medical model can accom-

modate the needs of families who have a handicapped child that may need medical attention. The outpatient department is set up to respond not only to a child's medical requirements but also to the family as a whole.

Parents are involved in their child's assessment and treatment program right from the start and are participating members of the multidisciplinary team. They can stay with their child 24 hours a day if they wish and can bring along brothers and sisters for visits.

The hospital has also set up a Parents' Services program which offers support to parents and families who need it. Parents' Services includes paid staff as well as some volunteers who act as advocates or as a liaison between families and the hospital. If the parents wish, staff or volunteers will go along with them to doctors' or treatment visits to make sure that they understand what is happening and that all their questions are being answered.

Staff or volunteers from the Parents' Services program often include parents who have had similar experiences or just individuals who know their way around the system.

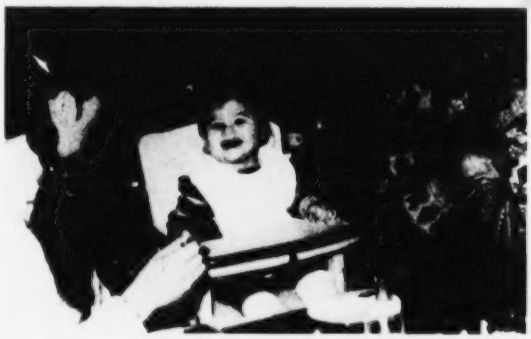
Parents who use the service have found it an effective way to deal with information they may not totally understand and see it as a way of making sure their rights are respected. The service is a valuable component in the hospital's approach to treating children as members of families and not isolated individuals.

Parent support groups

It is at the time of birth or when a handicap is discovered that parents most need the understanding of others who have undergone and can share the experience. Support groups such as "Pilot Parents" will be invaluable and professionals can help new parents by referring them.

When Julie and David found out that their newborn son had Down syndrome they were overwhelmed. This was something they were totally unprepared for and didn't know what to expect. Luckily, their doctor spent a great deal of time talking to them, explaining the baby's condition and encouraging them to treat him like any other baby. She also suggested that they might like to talk to someone from Pilot Parents who had had a similar experience.

When they felt they could discuss their situation with someone outside their family, Julie and David agreed to talk to Mark and Cheryl, the parents of six-year old Sean, who happened to have Down syndrome. After meeting Sean and talking with his parents, Julie and David felt much more optimistic about the future and realized they could still be a loving family despite their son's handicap.



Training and education for parents

Once parents overcome the initial adjustment period when they find out their child has a mental handicap, many are ready to begin helping their child develop skills which are often taken for granted in non-handicapped children.

One effective way in which parents can learn how to teach their children is for someone to come into the home and work with the family on a regular basis. This approach originated with the Portage Project in Wisconsin and has subsequently been adapted to meet the needs of various communities throughout North America.

A successful example of such a program is the Direct Home Services Program (DHSP) currently being delivered to families of children with handicaps by the Department of Social Services of Newfoundland and Labrador (Browne, Corbett, Gallant, Thompson, 1985). This is a community-based program for pre-school aged children, children up to seven years of age, or children who

are not yet ready to enter into a more advanced educational program. It is carried out in the child's home, so the parents have direct and constant access to the child's behaviours as they occur naturally. This means that the most likely goals that are chosen will be functional in the child's home. It also eliminates the problem of transferring what has been learned in a clinic or a classroom back into the home.

Referrals to DHSP are received from a wide array of sources, including public health nurses, general practitioners, psychologists, pre-school teachers, parents, friends and relatives of the child in need of service. However, the referral agency must ensure that the family in question wishes to become involved with the Direct Home Services Program.

An initial phone call made by a staff person determines the parents' level of knowledge of the service, explains it if necessary, assembles pertinent information and sets up an appointment if the parents so desire.

At the time of the first visit, an informal contract is outlined indicating the responsibilities of the parents and of DHSP. Information about the family is gathered, and an Alpern-Boll developmental profile is carried out with the child in order to determine the degree of delay and the areas in need of development.

Books are often lent, and a parent questionnaire is left with the family to determine the child's strengths and weaknesses. The DHSP Child Management Specialist conveys his or her views on the needs of the child and family during a weekly case conference, at which time decisions about services are made.

At the first regular home visit, the Child Management Specialist administers a test (Portage Guide to Early Education) to assess the child's present skill level. If a book was lent during the first home visit, it is discussed. Other educational methods are also used, such as audiotape, videocassette or film.

The parents and the specialist work together to set goals for the child. Beginning with the second regular home visit, the teaching process begins. The aim is for parents to assume more responsibility in curriculum planning and in the teaching process, until only one visit in three months, with monthly telephone contact, is required.

When Donna was a baby, she was not developing like other children. Her parents were anxious and unsure of what to do. Fortunately, the Direct Home Services Program (DHSP) had just begun operation.

Donna's mother recalls that three years ago, Donna just lay quietly all the time. She was unmoving, unresponsive and seemingly unaware of other people and her environment. Her mother remembers her own feelings of helplessness, when she realized she didn't know what to do or where to turn.

Now, Donna's mom is proud of her daughter's accomplishments and of her own. The little girl plays, notices things around her, approaches her parents and is learning to feed herself as she sits in her high chair. She is exploring the house and can climb the stairs.

Because of this training offered in their own home, families like Donna's can work directly with the member with a handicap. This will increase the child's skills and chances for more learning. Parents can take comfort in the fact that

they are not alone. Their communities and their government want to help.

Other participants in the DHSP made the following comments:

"This program is just fantastic! I don't know what we would have done if it weren't for the help that was given us. Kristine was quite uncontrollable and I just had no idea as to how to cope with her and our home life was chaos...

"At times it seems we are faced with an insurmountable task, and often the feeling that the problem is ours and no one seems to care or have any desire to help. The Direct Home Services Worker in my experience has been a great help in working with me and has also been someone I can talk to, as well. She has made me realize that there are people who care and are willing to help. I am very grateful to her."

"This program has taught me patience...all we needed was to alleviate these problems...the problems are not all gone but now I can cope..."

Money to families

If money can be regarded as an incentive, governments at all levels across Canada have created a vast disincentive for parents who wish to keep their children with a mental handicap at home. The government finances institutions, thereby valuing out-of-home residential centres more than a family environment.

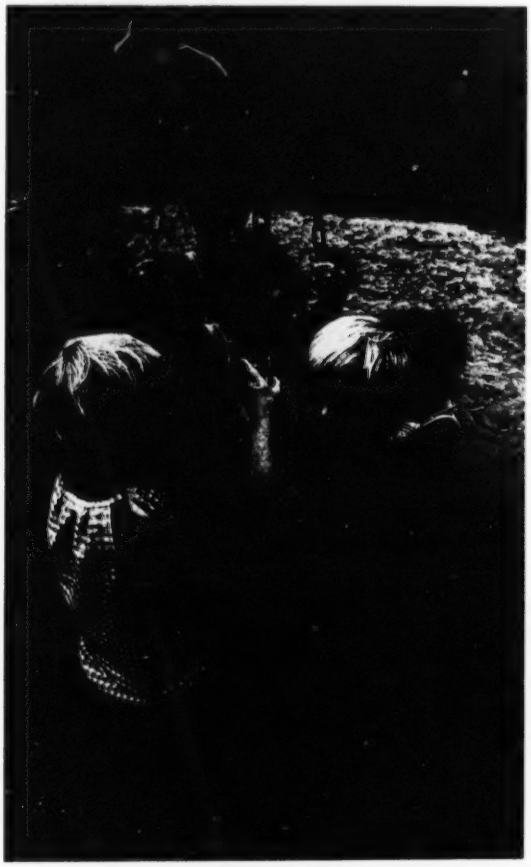
The reasoning, according to one authority (Trapper, 1979), could be as follows:

- politicians don't spend unless they have to;
- some, if not many, people believe that paying parents to keep their children is morally wrong;
- there is a problem with accountability for funds in parent subsidy programs;
- parents are no match for the service establishment in the battle for public monies;
- we perceive families with handicapped children as "deficient" or even "pathologic units" unable to function adequately within the accepted norms of society.

Yet several studies conclude that the following benefits are reaped by families who do receive subsidies:

- enable a family to care for their child with a mental handicap at home, thereby helping the child reach his or her fullest potential in a warm environment;
- improve the family's functioning and coping capacities, financially, socially and psychologically;
- increase the family's ability to purchase items needed by the child and attend to his or her needs;
- permit the other family members to do things they enjoy with each other or outside the home, thus enhancing the quality of each member's life.

When the programs have been studied, it has been demonstrated that children of families with financial subsidies had higher rates of growth in adaptive skills and greater reduction in maladaptive behaviours than families not receiving a subsidy.



The Government of Ontario makes funds available to families with handicapped children through its Special Needs and Services Agreements.

It is up to the parents to determine and obtain what their child needs in order for him or her to continue functioning as a family member. For families whose children are living at home, they may be eligible for up to $7,000 per year.

The money may be used for anything that will benefit the child, including services to the parents or the rest of the family which would make life easier.

Some families have used the subsidy for such services or materials as:

- *in-home help, so that parents can spend more time with their handicapped child or the child's brothers and sisters;*
- *after school programs for the child;*
- *summer camp;*
- *emergency respite care;*
- *special equipment.*

Respite care/in-home support

Respite care, planned or emergency care provided to the handicapped individual, in or out of the home, provide a break for the family. The resulting leisure time is essential to help them cope with any stress and enjoy the time they do spend with their child.

Families should be encouraged to recognize the signs of stress and to take advantage of any of a number of respite services:

- in-home skill instructors to assist with short-term behaviour management and specific skill development;
- sitters and companions;
- homemakers;
- temporary out-of-home living arrangements (weekends) with a host family or at a respite apartment;
- instructional training for parents;
- support groups for parents;
- year-round social and leisure activities for children, adolescents and young adults with a focus on integrated recreational opportunities.

Community Respite Service (CRS)

Gershy Mayman is a young man of 22. He lives in Manitoba, and on September 7, 1985, he was moved to write to the Winnipeg Free Press about the impact of a support service in his family's community.

His letter says it all:

"Over the past year and a half I have been fortunate to receive help from the Community Respite Service. This is a service where an attendant comes into your home and stays with you, takes care of you, etc. so that your parents can go out or away. Because I live at home it is a strain on my parents. They can never go away like other parents. This way they can leave me and know that I am in good hands. This gives them a rest and a chance to do something with my younger brother. I think it is very important for my younger brother to have this time with them.

"The attendants are about my age. We do things together like going to eat or to a movie. I feel good being able to do this because it is not so great at 22 to always have to go out with your parents.

"I am one of the lucky ones because my mom and dad are always there for me but they need some time on their own so that they can have the energy to continue to care for me."

The Community Respite Service (CRS) of which Gershy speaks began in 1983. It was founded by seven groups who were concerned about the level and availability of community support to people with handicaps and their families.

The unusual feature of the CRS is that the Board of Directors doesn't just include parents and people with handicaps; it is controlled by them. Who else is in a better position to monitor quality and determine what works best, than the people who use the service?

Taking action to "build" families

- We must break the long and regrettable tradition of removing children from the care and support of a family and community, and segregating them in institutions or in any other setting which is not a family home.

- The human service system as a whole must be redesigned to support, not supplant, families.
- Our education and assessment systems must be modified to better serve the needs of children who may be at risk of acquiring handicaps.
- We must educate parents on better child-rearing practices, and provide high-risk infants with the care, stimulation and training which may be missing from their homes. Handicaps must not be further compounded by unfavourable social environments.
- In instances where it is not advisable to keep children with a mental handicap with their family, alternative, permanent families such as foster homes or group living experiences are preferable to institutionalization. This community-living situation gives children the sense of continuity, commitment and love to which they are entitled, and which in turn will help them reach their potential. Remember, Superman was a foster child!

- More public funding must be made available to families who keep their child in their homes, recognizing that they sometimes need specialized assistance, individual respite and other services known to be effective. Government subsidies and incentives will lessen institutionalization, reflecting the public's shift in perception.
- Authorities must intervene rapidly and effectively in the instance of a family breakdown or, ideally, before the breakdown occurs and any damage, such as abuse or neglect, has been done. However, social services must remain a support to the family, not vice-versa. Services are not substitutes for families.
- Professionals must encourage parents of children with mental handicaps to form support groups: parents linking up and supporting one another in the face of the situation of having a child with a mental handicap. It is natural for them to share their experiences and emotional support with one another, as only people who have felt the impact can. Well-organized groups such as "Pilot Parents" are taking root across Canada, with the goal being to contact new parents, whose need to talk is most urgent.
- Government must establish in public policy a clear objective that public resources will support:
  - the parent-child relationship
  - the quality of the home environment in other social, cognitive and physical dimensions.
- Governments and professionals must phase in escalating allocations for family support programs by decreasing funding for children's institutions, group homes and other out-of-home living arrangements.
- Professionals must establish procedures for screening and identifying "at-risk" families in social, biological, medical and nutritional terms, and provide direct support to "at risk" families even prenatally.
- Policy makers must replace the means test as an eligibility requirement for publicly supported assistance with a "degree of risk" test. This will permit eligibility to be determined on risk factors in medical, social or psychological terms.

SOCIAL AND PHYSICAL INTEGRATION

No matter how strong the families of young handicapped children are, within themselves, and through external supports, they need to reach out to the community, build relationships and make inroads for their children. Programs and services must be integrated to bring handicapped children into regular contact with their non-handicapped peers.

It is often difficult for parents to consider regular pre-school programs for their sons and daughters when all they've heard about since the child was born is "special" services. Yet attitudes are slowly changing and integrated pre-school programs are becoming much more common.

In the same way, more and more handicapped children are living at home with their families. As neighbourhoods become visibly "integrated," non-handicapped children become accustomed to having handicapped children in their midst. In many cases, they become friends.

The following story tells of such a friendship and provides an inspiring scenario for parents of young children with handicaps.

Our daughter, Shawntell, is almost 12 years old. She is a beautiful young lady who enjoys swimming, playing video games, watching movies, listening to records, watching television and playing with her friends.

Shawntell also happens to be disabled. She has learned many new skills over the last few years. She is now able to walk for short distances with no external supports. Shawntell has a small vocabulary that includes "yes," "no," "daddy" and "hi," and she also makes her needs known through body language.

Because Shawntell attended the neighbourhood elementary school, rode the regular school bus and participated in the local neighbourhood activities, she met and started to become friends with a host of typical children, including Tanya.

Tanya has become a close friend to Shawntell. Over the last two years the girls have grown closer and closer. Their relationship, which started in a local buddy program, has become just like any other good friendship between two girls. There has been a growing understanding and respect on both their parts as they learn more about each other. This has taken time and is a continuing process. The girls see each other often and enjoy their friendship. They do many things that are typical of children who are 12 years old — going to the movies, buying records, watching television, listening to music and playing video games.

What does the future hold for Tanya and Shawntell? Tanya is 12 years old. Over the next few years, she will be involved in many new experiences that will probably change her life. She will become more involved with boys, school, parties, other friends and many new dreams and exciting adventures.

We believe that Shawntell will continue to have a place in Tanya's life. We know that Tanya has a place in Shawntell's life. The future for these girls can include a continued relationship that will only blossom and grow as time goes by. (Strully, 1985).

REFERENCES

Bromwich, R.M. (1976). Focus on maternal behavior in infant intervention. **American Journal of Orthopsychiatry, 46**(3), 439-446.

Brown, N., Corbett, A., Gallant, D., & Thompson, E. (1985). Direct Home Services Program: Service plan for a community based developmental service. **Canadian Journal on Mental Retardation, 35**(2), 8-12.

Canada Dept. of National Health and Welfare. (1982). **Ad Hoc Committee on National Strategies.** Ottawa: Author.

Charney, E.B., et al. (1985). Management of newborns with myelomeningocele: Time for a decision-making process. **Pediatrics, 75**(1), 58-64.

Crocker, A.C. (1982). Current strategies in prevention of mental retardation. **Pediatric Annals, 11**(5), 450-457.

Harrigan, J. (1983). Prenatal and obstetrical factors in mental retardation. In American Association of University Affiliated Programs for Persons with Developmental Disabilities (Ed.), **Developmental handicaps: Prevention and treatment** (pp. 291-304). Washington, DC: AAUAP.

Milunsky, A. (1983). Genetic aspects of mental retardation: From prevention to cure. In F.J. Menolascino, R. Neman, & J.A. Stark (Eds.), **Curative aspects of mental retardation: Biomedical and behavioral advances** (pp. 15-25). Baltimore: P.H. Brookes.

Scriver, C.R., et al. (1985). Quebec network for genetic medicine. **Canadian Journal on Mental Retardation, 35**(2), 4-7.

Steinman, M.E. (1979). Reaching and helping the adolescent who becomes pregnant. **American Journal of Maternal Child Nursing, 4**(1), 35-37.

Strully, J. (1985). Teach your children. **Canadian Journal on Mental Retardation, 35**(4), 3-11.

Trapper, H. (1979). Barriers to a family subsidy program. In R. Bruininks, & G. Krantz (Eds.). **Family care of developmentally disabled members: Conference proceedings** (pp. 79-84). Minneapolis: University of Minnesota.